

## **PART 2**

I don't know what drug you're talking about, but they're not giving it to my husband. Do you know what I'm saying? Where is this miracle drug at, that makes him not hear voices anymore and not do all this stuff, because, do you know what I mean? And my husband takes a lot of medication, but he doesn't take anything that does that. So, this is what I'm saying –

### **Narration 9**

*Families caring for patients with mental illness need information to support them in their roles as caregivers and to interact effectively with the treatment team. A good way to get families information is by offering family workshops or conferences.*

Because I had to come up with my own stuff. No information, not knowing anything about schizophrenia and how to cope with it. So, this is what I'm saying – when things do occur, when information becomes available, we need to get that information, too. You know? I need to know there's a miracle drug. I want some, I want some for him, do you know what I'm saying? I mean, look, and I've got all this stuff, I'm writing down everything, because I need to know. People don't understand how hard it is to take care of somebody with a mental illness.

Families appreciate attending family conferences, because it gives them an opportunity to learn more about their loved one's diagnosis, about the medications, side effects, compliance issues. It gives them a chance to meet the clinicians that are treating their loved one, and especially to meet other families who are dealing with the same issues that they're dealing with, and often feel very alone in dealing with those issues.

I thought that, just in terms of opening up the session, I wanted to really emphasize the importance of families, involving families and patients actively in treatment, because I know the audience here is both family members, as well as veterans who are patients. So, it's really important to think of us all as a team. So, that's really how we think of it today. Mental illnesses are brain disorders, that when they occur, they affect the family in very profound ways. They also affect the patient who has the illness, and that our job as health care providers is to really partner with the family and the patient to try to help things be as good as they can possibly be, and that partnership is extremely important, and if there's no other message you get out of my talk this morning, it's the importance of that partnership between the family, the treatment team, and the patient to really have things go well.

### **Narration 10**

*This partnership means a sharing of information and open lines of communication. Both families and patients need to keep the treatment team informed.*

That's exactly what I'm talking about, the family is definitely important to interact in your treatment and in your therapy, so you can all be on the same plane. My family experience has been, I've been through a lot of this not knowing what I had or not knowing what I was going through. And I know there was something wrong in my life, and I didn't know.

I think that we're all in this together, or we ought to be. That the illnesses are very challenging to treat, and the treatments are often not as effective as we want, even under the best of circumstances. So, it's a shame, I think, to have barriers that exist between practitioners and families, practitioners and patients, patients and their families, that get in the way of trying to get the best treatment. So, the idea of a partnering kind of approach to this, is to try to get everyone to work together as best as possible, I note to the practitioners who are in the audience, and who might listen to this, it's really our responsibility to step up to the plate and foster it.

#### **Narration 11**

*Another area being addressed in this family conference is the importance of meaningful employment opportunities.*

And I wanted to know how I could do better within my weight program, I wanted to know what the other great programs that would help me stimulate my mind and keep me from not being, what you said, a couch potato. Really, to me, it's to be around other people and to learn how to deal with other people.

What I'd like to do today is to talk to you about a service called "Supported Employment," which is related to simply put, helping individuals to get a job and keep a job. Work helps us to live an interesting, productive, and useful life. Because we're not just talking about going out and getting a job and that's it, because that really does a disservice to the person who is also working on managing their mental illness. We're talking about helping someone to get a job in a structured way, so that they're getting the support that they need to work, but also to continue to work on managing their illness, getting back into the community, and living a full life.

#### **Narration 12**

*Both employers and patients regularly report improvements in self-esteem as an outcome of work programs.*

It feels really good. The best thing I can tell you is they'll go home, they're not scheduled to work, but they come in, but they come in. What I like is that if they have a problem, they're not afraid to talk about it, they're not afraid to talk to me about it. I've had people who I've been told couldn't do but so many things. Well, after a year, I get them to do five or six things. Just, it's patience, it's

having trust in each other, and being able to let them know, I've been where they've been, and here I am.

I'm a Vietnam vet. I've experienced a lot of anxieties that these people feel, and I think that if they work in a structured environment, given the opportunity to the individuals to think for themselves, only can be positive for them.

### **Narration 13**

*Individual differences, preferences and personalities must be taken into consideration when structuring a work program if it's to be successful.*

He has got a pretty good education, right? And he is a custodian here, and I'm wondering whether, I mean why doesn't he try to go further than the custodian. But he told me – because I talked to him – he said he likes not being around a lot of people. So, this job is like being to himself. And it's not much money, but he doesn't mind that.

Yes, and what you just described really excellently touches on the consumer preferences and interests. The job should be based on what the person's interested in, what they like to do, what they're comfortable in, that helps them to manage their illness and to progress, and to be able to get out in the community and do the type of things they'd like to do.

### **Narration 14**

*Family educational workshops can address a wide variety of areas that are of concern to families and patients. They are an excellent way to provide education that will support families as they become a part of the treatment team.*

### **Narration 15**

*Planning a family educational workshop is very feasible on the local level. It involves recruiting local clinicians with knowledge about a particular area of mental health treatment to present at the conference, and then engaging clinicians to encourage patients and families to attend.*

### **Narration 16**

*A detailed description of how to organize a family conference can be found in the brochure accompanying this video, or at <http://www1.va.gov/visn5mirecc/> under educational programming.*

### **Narration 17**

*In addition to providing family conferences for veterans and their families, it's important for clinicians to refer families to other educational opportunities. For example, the Family to Family program, developed by the National Alliance for the Mentally Ill, or NAMI, is a free 12 week course available in most states. This educational program is taught by 3,500 trained volunteers and to date has graduated over 100,000 family members.*

It's hard, you know, when you need help and what do you do?

One of the things that clinicians really need to know is that families, no matter how long they've been dealing with a relative who has a mental illness, are always hungry for information about mental illness, about how to work with their family member.

In the beginning, when we were first notified the diagnosis of our family member, we were devastated. We felt lost, we didn't know what was coming next. We wanted to know how long the illness was going to last, can they ever work again, you know? We were just bombarded with questions. We just didn't know what to expect, or who to ask, or who to go to, and we didn't really get any answers.

And in a case where a patient is intelligent, as our son is intelligent, and can throw the doctors a curve at times, if the doctors aren't willing to listen to the family members, who live with this person, day in and day out, there is no way possible they can know what the effects of the medications are, the dosage being correct, or even if the patient is telling the doctors the truth. That's all up for grabs, and the less family involvement, to me, the less chance there is of a recovery to the best of their ability. And I think anything other than that is shortchanging the patient and not fair to the veterans.

Because, like Bill said, I'm with him every day, 24 hours a day. I know every episode he has, I know every personality that he talks to, I know every – I can look at his face and see when he's getting ready to go into an episode or whatever, you know? So, I think that that information is more important for them because they only see a patient for 10 or 15 minutes, once a month. You know, the importance of hearing what the family has to say is going to determine whether or not your family member gets better.

There's a problem with keeping that ball rolling, and to make progress. We're finally seeing some now, but it took a long while, and if you're not persistent and you don't have knowledge, and it's hard to get that knowledge, it's so difficult to get that knowledge.

How did you go about getting that knowledge?

From NAMI, NAMI has helped us tremendously. Hearing other stories and what other people have done has just really given us that extra step to know that we have a stand, and that we deserve a stand, and the patient of all, the loved one definitely deserves one.

So, you feel like you've gotten some confidence?

Confidence, knowledge, um –

Knowing what questions to ask?

Yes, at least it's guided us in the right direction. We might not be an expert, but it certainly has opened the door.

**Narration 1 8**

*Families sharing concerns, feelings and experiences and gaining knowledge make Family to Family an excellent foundation to begin participating with the treatment team.*

**Narration 19**

*Contact the NAMI help line at 1-800-950-NAMI for information about family-to-family in your area.*

**Narration 20**

*Nationally recognized experts present a strong case for including families as part of the treatment team.*

Family to Family gives families a sense, first off, I think of not feeling alone and isolated, which is the initial impact of the trauma of mental illness, that suddenly people – life seems to almost fall away, and so the first thought that we have is to get people together, so that they can understand that they're not alone and put them in a place where the people touching him, come through the experience that they are now helping in life.

Probably the most important thing to keep in mind is involving the family in the ongoing process of care, actually makes the care better, and I think it actually makes it easier for the clinician in the long run, because you really have the treatment team, which involves the family, are often the primary support system for the patient. We do know, pretty clearly, that involving families in terms of educating them about the illness and about treatment, providing them with support, helping to address some of the problems that they face, and providing support and care to the patient, and providing them access to crisis intervention, really substantially improves the outcome of care.

Virtually every set of practice guidelines that describe what is evidence based practice in the care of people with schizophrenia, and, to a lesser extent, although also other severe mental illnesses, require that efforts are made to engage the family, to provide a family psycho education, which is a specific, very well described, manualized program that includes families in the care of the patient. So, if this is not being provided, if this is not available, then the system of care is not providing care that is consistent with high quality, evidence based practice.

If there's a change in the patient's condition that the patient may not be aware of, or many not have insight into, that suggests a worsening of the condition, then the doctor needs to be informed about that. Because that involves determining whether or not there's the beginning process of a relapse. If the doctor knows this, he has a chance to try to choose a drug or dose level that's most compatible with the patient taking the drug, and figuring out what the family can do to help be sure that the patient takes the medication in a different way.

In terms of managing medication, families play multiple roles. They can give us information about a person's response to medication, side effects to medication, whether or not the medications are causing disability during the day, for instance, excessive sedation, whether the person is actually taking the medicine as they say they're taking the medicine. Information about past response to medications, what works, what doesn't work.

There are often times when clinicians don't understand the importance of involving the family, and site their personal reasons for this. This most prominent one is that they don't have time. We work with a lot of patients under a lot of pressure and sometimes patient feel their job is merely to give medication, send the patient on his way and hope for the best, and don't get involved with real case management. If a clinician tells me that they don't have time, we can often point out that without getting the families involved, they will spend more time with the patient, because the patient will not comply with the treatment, require treatment hospitalizations. The clinician will always be putting out fires, and usually and most inopportune times.

### **Narration 21**

*These experts have shared with you the importance of including family as part of the treatment team. Research clearly demonstrates that treatment outcomes improve when families are included.*